

# 'Consumer' should be a taboo word in public services

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**Human rights are a powerful idea, but they only exist as words and actions. If we don't get the words right, then we can end up with the wrong actions.**

**There is a particular word I'd like to challenge. That word is 'consumer'.**

I have lived in Australia for more than a year now and have been exposed to this word many times. It is used across Australia to describe people who use public services, including health services. It is used to describe people using a service which should be designed to uphold their human rights. When people talk about 'engaging' or 'involving' the public in improving services, they call it 'consumer engagement'. I have been told this is to imply 'citizens with rights' or 'equal partners' (Hill, 2011).

A look into the origins of the word 'consumer' using the Online Etymology Dictionary shows that it has its roots in a word which means 'under', 'below' or 'sub' and the very origins of the word are associated with a transactional merchant relationship where the 'consumer' takes goods or services. In the same Dictionary, the word's Latin root 'consumere' means to 'to use up, eat, waste' (for example, 'consumed by fire').

For me, this word in no way implies an 'equal partnership'. And yet, in Australia this word is often used to try and describe exactly that.

I have asked a number of people here who are experts on this matter and who I respect enormously, including a former CEO of the Health Issues Centre and staff at the Consumer Health Forum. The impression I get from many of these experts is that no one really likes using the word but it is felt to be far too entrenched to change now.

Another (almost apologetic) argument goes along the lines of: even though we use the word 'consumer', what we actually mean is "patients and potential patients, research participants, carers, consumer organisations and members of the public" (NHMRC and CHF, 2014, p.4). This shorthand is acceptable as the people who need to understand it do. Personally, I do not accept this argument, just as I wouldn't accept the defence of any derogatory and inappropriate word which excludes people.

As a newcomer to this culture, but as a native speaker of English, I struggle to use this word and I feel embarrassed to use it. This might sound like an extreme thing to say, but it makes me ashamed to think of people affected by cancer or other diseases described as 'consumers', just as it would if they were called 'customers' (as some charities in the UK do internally).

Having worked for a health charity and in the world of health research in the UK, I am accustomed to the concept of 'public involvement'; at the heart of this is the idea that anything for the public should be done "with" or "by" members of the public rather than "to", "about" or "for" them' (INVOLVE, 2015). While this wording originates from health research and attempts to 'link science and democracy' I feel the sentiment applies to any public service as it is essentially democracy in action.

Orwell wrote of democracy that 'not only is there no agreed definition, but the attempt to make one is resisted from all sides' as we may 'have to stop using that word if it were tied down to any one meaning'. (Orwell, 1946) I believe the same is true of all words used to describe the ideal of 'public involvement', be it 'engagement', 'community participation' or the newer terms 'equity and participation'. Some of these terms are used almost interchangeably, often to suit the need of that organisation delivering the service; a sceptical person might get the impression that definitions are perhaps even wilfully opaque.

I like the word 'public' because it includes everyone and everyone knows what it means. An exhaustive definition of the word public in a health setting was written by the Health Research Authority. They define 'public' as:

*Patients, potential patients or members of the public including those with known genetic dispositions, carers and people who use health and social care services as well as people from organisations that represent people who use health and social care services. (Elliot, 2013, p. 12)*

Looking at the word 'public' next to the word 'consumer', I feel that the latter has become institutionalised jargon; potentially excluding the very people it is trying to include. It is used to describe the general public (for whom the services are for, and who pay for them) and yet ask any member of the public and they may not know that the term refers to them. Rather than empowering people, I feel the word now disempowers them.

Internationally, the word 'consumer' may also cause confusion. I am currently involved in a piece of international research with the Cochrane Collaboration on priority-setting. When writing the documentation, we had to be careful not to use the word



'consumer', as our colleagues (and the public) abroad would not understand this term to mean the general public.

There are some interesting examples of the shift from using the word 'consumer' to 'partners' and 'public'. For example, I worked on developing a course which was originally called 'Consumer Research Skills'. When the National Institute for Health Research and Macmillan Cancer Support had finished development, it was instead called 'Building Research Partnerships' (McMillan Cancer Support, Learn Zone, 2015). I'm sure that the word 'partnerships' will transmute into other terms in the future, but the notion of a 'consumer' was replaced by that of equal partnership.

A recent UK report about the ethics of data sharing referred to 'mere consumers, reduced to accepting or refusing an option presented to them, or choosing between several available 'offerings'' (Nuffield Council on Bioethics, 2015); while the Labour party in England wrote that people should not be 'mere consumers of services but genuine and active partners in designing and shaping their care and support' (Hudson, 2014), creating a distinction between these words.

The Nuffield Council on Bioethics (2015, p. 90) recently wrote 'it is no longer a matter of evaluating the different trade-offs as a consumer but instead about negotiating between the moral interests of different participants (where one 'participant' may represent the 'public interest')'.

Despite this international move away from the word 'consumer', Australia continues using it, hoping that the rest of the world will understand it. Current Australian Government language in Standard 2 'Partnering with consumers' describes consumers as 'people who use, or are potential users of healthcare services' (Australian Commission on Safety and Quality in Healthcare, 2014, p. 3). That could simply be reworded as 'everyone'.

My perspective on this concept is not a new one in Australia. Similar ideas can be found in an article published in 1997 in *Health Issues*. Jill Sutton (1997, p. 6) challenges the word 'consumer' as representing the idea of commodifying health services into something that is just 'bought and sold', creating a split between being a 'consumer or a provider'. Sutton describes this mindset as "a divisive intrusion into the way humans behave when they need and care for each other".

The implication that the 'market model' and 'consumer rights' are the best humanity can offer is questionable. The reality in public services is that we will never be far from the famous Henry Ford's quote about the Model T car: "you can have any colour you like, as long as it's black". This is not consumer choice.

Because health is not a simple a 'market transaction' (Draper, 1997), this inappropriate business language should have absolutely no place in creating partnerships with the public, for whom these services exist and are funded by. It especially has no place in health and social care. 'Consumer' and 'stakeholder' are transactional words, reducing experience to a tradable commodity.

Human rights are not a commodity; dignity does not have a price. Everyone should use language which supports the public to be involved in planning and evaluating their own services.

We are all people and we all have inalienable human rights. No one describes themselves or their families as 'consumers', so let's start calling people 'people', and the public, 'the public'. We already have 'public health' and 'population studies' in medicine. Equally, when we want to involve patients specifically, say 'patient', remembering that if we want to involve people, we need to make sure our language does not unconsciously exclude them. For example, using 'carers' or 'care-givers' and excluding friends and family who might not identify with that word.

By using a euphemism, we unconsciously create gaps in meaning, and these gaps exclude people. For example, in Canada they say citizen, when I think they mean 'public', thus unconsciously excluding asylum seekers, refugees or in fact anyone living in a country who isn't a citizen.

It is worth saying that I do not think 'public involvement' is the perfect term and any acronyms such as 'PPIE' (which stands for Patient and Public Involvement and Engagement in the UK) are at the worst end of jargon. But I feel the words 'public', 'involvement' and 'participation', when used in full, are closer to the core ideals of shared control and accountability, to which all these terms aspire.

Similarly, I do believe a 'consumer perspective' can be a helpful framework to examine a certain kind of relationship, but it cannot be the only one we use in public services, as it does not capture so many aspects of our relationship with public services.

So next time you're searching for a word to describe the public, try using 'the public', or even 'people' and see what happens.

#### About the Author

*Jack has led the development and implementation of an internationally recognised model for building partnerships between the public and researchers. He has worked for government, leading charities and universities, including the UK's National Institute for Health Research and Macmillan Cancer Support. He has partnered with the World Health Organisation, the Cochrane Collaboration and community organisations across the UK, Europe, Australia and Asia. Since moving to Melbourne last year, Jack has worked on projects with the Department of Health and Human Services, Cochrane Australia, La Trobe University and Health Issues Centre. Jack volunteers his time as an Editorial Board member for the new open access journal 'Research Involvement and Engagement'. He has also volunteered internationally with not-for-profit organisations, sharing his knowledge in learning and development and public involvement.*